# Transitions in Rheumatic Disease: Pediatric to Adult Care

Stacy P. Ardoin, MD, MS

**KEYWORDS**

- Transition • Rheumatology • Adolescent • Young adult self-management
- Chronic disease • Health care outcomes

**KEY POINTS**

- Young adults with a broad spectrum of rheumatic disease are vulnerable to poor health and outcomes, highlighting the importance of optimizing the transition to adult care.
- Too often, young adults are ill-prepared for adult care and face substantial challenges, including insufficient education and guidance, interruptions in care, and poor health and vocational outcomes.
- The ideal transition to adult rheumatologic care begins in early adolescence when patients, families, and pediatric providers start to prepare young adults to integrate easily into care with a prepared and proactive adult health care team.
- Primary care and rheumatology providers need to develop, study, and implement interventions to improve transition and transfer processes and health care outcomes for young adults.
- Quality improvement approaches such as the Six Core Elements of Health Care Transition offer opportunities to improve transition care for teens and young adults.

## INTRODUCTION: WHY IS TRANSITION FROM PEDIATRIC TO ADULT CARE IMPORTANT?

The successful transition of the young adult patient with chronic disease to adult care is an important milestone in pediatric medicine. The ability to transition care, which for many with serious chronic illnesses may not have been possible in previous eras, reflects improved survival because of advances in preventive care and management of acute and chronic illness. In fact, 90% of children with chronic health conditions survive into adulthood, and around 500,000 young adults with special health care needs become adults each year.[1] Among the estimated 18 million adolescents and young adults in the United States 18 to 21 years of age, about one-quarter have chronic health problems, including rheumatic diseases.[2] Unfortunately, the transition from pediatric-centered to adult-centered health care can be a vulnerable period for young

---

Disclosure Statement: The author has no relevant disclosures.

Pediatric Rheumatology, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205, USA
*E-mail address:* stacy.ardoin@nationwidechildrens.org

Pediatr Clin N Am 65 (2018) 867–883
https://doi.org/10.1016/j.pcl.2018.04.007
pediatric.theclinics.com

adults with rheumatic and other chronic diseases. Hazards include gaps in continuity of care, poor treatment adherence, delays in establishing adult care, differences between adult and pediatric health care systems, inconsistent availability of appropriately trained adult providers, self-management challenges, and unstable medical conditions. The 2014 Institute of Medicine report, "Investing in Health and Well Being of Young Adults," highlights the transition from pediatric to adult health care as an important component of improving the health of young adults, particularly those who have chronic disease.[2]

Without needed support and input from adult and pediatric providers through the transition process, young adults often experience decreased quality of care, increased health care costs, and poor health.[3] Young adults are more likely to use the emergency department and to have lower health status and higher mortality compared with older and younger cohorts.[3–9] The situation is even worse for minority and impoverished adolescents and young adults, who report being less likely to receive transition counseling, which likely contributes to health disparities for these populations.[7]

### *Childhood-Onset Rheumatic Diseases Become Adult Problems*

Most childhood-onset rheumatic diseases persist into adulthood. For example, more than half of the patients with juvenile idiopathic arthritis (JIA) experience active disease in adulthood, requiring ongoing management of immunosuppressive medications.[10–12] Young adults with JIA are at increased risk to drop out of medical care, and some adult rheumatologists express discomfort in the medical management of JIA.[13–16] Childhood-onset lupus is always a lifelong disorder. It is associated with high acuity and frequent hospitalization, risks of disability even in childhood, and higher morbidity and mortality compared with adult-onset lupus.[17–20] Transitioning young adults with lupus are at risk for significant gaps in care.[20] North American parents of youth with inflammatory myopathies report low awareness of transition policy and lack of a transition plan or medical summary.[21] In a retrospective, single-center study of 31 patients with a variety of chronic rheumatic diseases, 58% had active disease when transferring to adult providers, 30% were hospitalized for disease flare in the year before transfer, and 30% experienced an increase in disease activity in the posttransfer year.[22]

Many young adults with chronic disease are also less likely to achieve college education and maintain employment and will have lower income compared with those without chronic disease.[23] Young adults with JIA tend to have higher rates of unemployment, with some studies showing lower and others showing comparable education attainment compared with the general population.[24–27] Those with childhood-onset lupus similarly have less employment than their peers despite similar education.[28] Young adults with rheumatic disorders report problems with absenteeism, job disruptions due to illness, and productivity loss.[29] They also express concerns about employers' attitudes toward young adults with chronic diseases.[30]

## WHAT ARE THE BARRIERS TO SUCCESSFUL TRANSITION?

Several national surveys demonstrate that most adolescents, young adults, and their parents are inadequately prepared for the transition to adult care.[1–5] Although some of the barriers to successful transition to adult care are disease specific, most young adults experience similar challenges across the spectrum of chronic diseases. A recent systemic review examining 57 disease-specific chronic illness transition studies identified the following common thematic barriers to transition: health care access/insurance; patient, parent, and provider beliefs/expectations; relationships; and